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Submission to the 2020-21 State Budget Community Consultation

Thank you for the opportunity to make a submission to the 2020-21 State Budget Community Consultation.

Please note that this submission contains sensitive information in the two case studies at Annex 1 and Annex 2. While the clients' names have been redacted, they will likely be identifiable from the context. In the event this submission is published or otherwise released, we ask that these case studies be removed.

This submission makes recommendations about ***the continued funding of independent advocacy services*** provided by The Association for Children with Disability (Tasmania) Inc. (hereafter, ACD). Advocacy services are a valuable community resource in Tasmania. These services require continued funding to sustain effort aimed at achieving an inclusive society for people with disability and their parents and carers.

Advocacy is the process of actively supporting an individual or group and representing their views to their benefit. In this way advocacy ensures that the voices of people with disability are heard in matters that affect their lives. Independent advocacy services aim to ensure Tasmanians with disability and their parents and carers can enjoy the benefits of living in "a fully inclusive society that values and respects all people with disability as equal and contributing members of the community" (in the words of *Accessible Island: Tasmania's Disability Framework for Action 2018–2021*).

The importance of independent advocacy services in disability support and care has been widely recognised, including by the federal Government, federal parliamentary committees, states and territories, and by the Productivity Commission. The Australian Law Reform Commissions' definition of advocacy, as it pertains to children and young people, summarises the importance of advocacy in assisting children and families to:

- *navigate the complex maze of bureaucratic processes,*
- *resolve complaints and conduct enquiries into individual concerns,*
- *access services or obtain redress for complaints and problems,*
- *encourage the development of structures to enable children and young people to be active participants in the decision-making processes affecting their lives, and*
- *monitor compliance and international obligations, scrutinise legislation, programmes and initiatives.*

These services also deliver wider benefits to the community, including significant budget savings, as demonstrated by Cost-Benefit Analysis commissioned by Disability Advocacy Network Australia (September 2017).

ACD is the only funded independent advocacy service in Tasmania that specialises in advocacy on behalf of families and children and young people with any type of disability or disabling condition. State Government funding importantly ensures a robust advocacy mechanism for the most vulnerable children and young people in the state; providing accountability of services and enabling the government to access independent advice, from the experiences of these children and their families, for which to reflect on service needs and practice and policy standards.

It is therefore vitally important that Tasmanian Government funding of ACD continues when the current funding agreement ends on 30 June 2020.

Without continued funding, ACD would not be able to continue to provide its services. From its offices in Hobart, Devonport and Newstead, in 2018-19, ACD Advocates responded to 194 referrals from parents, carers, and guardians who required advocacy to resolve 489 primary issues. While these numbers were slightly down on the 2017-18 figures (213 referrals to resolve 538 primary issues), they have continued to be high since 2016 and the cessation of the NDIS trial in Tasmania. Time spent resolving individual cases increased on average this year by 30 minutes due to the complexity of the issues people reported. In 2018-19, 44 per cent of children and families presented with issues that were assessed as having high impact and urgency (compared to 34 per cent in 2017-18, 32 per cent in 2016-17 and 20 per cent in 2015-16). In 2018-19, ACD Advocates also provided information requiring less than 1 hr. of staff time to young people with disability, family and professionals on 497 occasions.

The implementation of the ***National Disability Insurance Scheme (NDIS)*** continues to place additional demands on the ACD’s advocacy program. The NDIS has significantly improved the financial capacity of people with life-long disability and their families to purchase needed services, supports, and equipment and technology. However, ACD has experienced continuing demand for its services in relation to the NDIS as people grapple with how to access the NDIS, navigate its requirements and compile the evidence needed to support their claims.

In addition, the ***Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*** has and will continue to require ACD’s involvement through to 2023. Given our nearly two decades of delivering advocacy services, and our extensive family stakeholder networks in the community, ACD’s contribution to the work of the Royal Commission is vital to ensuring Tasmanian experiences are reflected in the outcomes and recommendations of this once-in-a-generation opportunity. However, engagement with the Royal Commission is very resource-intensive. As described in this submission, ACD’s input to the Royal Commission has already meant considerable demands on staff resources, and this is likely to continue and increase over the next three years. We therefore ask that the Government make provision in the Budget for additional funding in the years 2020-21, 2021-2022, and 2022-23 for ACD’s engagement with the ***Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.***

This submission expands on the above points and provides the evidence base for our recommendations.

Caroline Pegg
Chief Executive Officer

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Recommendations:

The Association for Children with Disability (Tasmania) Inc. (ACD) recommends:

1. That the Tasmanian Government make provision in the 2020-21 State Budget for ongoing funding of ACD Tas to provide independent advocacy services to children and young people with any type of disability or disabling condition and their parents and carers, when the current funding agreement terminates on 30 June 2020;
2. That the amount of funding reflects the current level of $367,601 plus GST in 2019-2020 (plus Equal Remuneration Order and Indexation)
3. That the Tasmanian Government make provision in the 2020-21 State Budget and 2021-2022, and 2022-23 out years for base additional funding of $115,000 (plus Equal Remuneration Order and Indexation) to meet the additional individual advocacy and family stakeholder engagement demands arising from the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

The importance of advocacy services

Around four million Australians, or one in six people, have a disability. People with disability continue to experience fewer opportunities in life and they face physical, social and cultural barriers to simply being recognised as equal members of the community. Discrimination against people with disability remains a widespread and everyday occurrence.

Independent advocacy for people with disability can be defined as speaking, acting or writing – with minimal conflict of interest – on behalf of the interests of a disadvantaged person or group, in order to promote, protect and defend the welfare of and justice for either the person or group. Independent advocacy enables people with a disability to enjoy the same rights as other Australians, to make choices about the decisions that affect their lives, to pursue goals that are important to them, and to live independent lives and participate fully in social and community life.

Independent advocacy is crucial to upholding, promoting and protecting the rights of people with disability and ensuring their voices are heard in matters that affect their lives. These rights are enshrined in international instruments such as the United Nations Convention on the Rights of Persons with Disabilities, which Australia has ratified, and the principles are reflected in national and state laws.

What sorts of things do independent advocates deal with?

Independent advocates support people with a disability in a range of ways. They help people with a disability and their families and carers to negotiate appropriate and tailored service delivery in settings such as childcare, schools, hospitals, accommodation services, shops, transport and in their dealings with government departments. They support people who might be caught up in the criminal justice system or in other legal processes such as care and protection, guardianship matters or who are trying to claim their human rights.

Independent advocates also write submissions and consult with governments and other bodies to raise awareness and influence community change that promotes and protects the rights and interests of people with disability. They speak publicly and highlight situations where people with disability are treated unfairly.

Preventing abuse and neglect

Advocacy services are also a critical safeguard against abuse and neglect of people with disability, which unfortunately remains widespread as evidenced by continuing media reports and official inquiries. Effective independent advocacy services can help to prevent abuse and neglect, and support people with disability and their families to report abuse and neglect when it occurs.

In November 2015, a report by the **Senate Standing Committee on Community Affairs** highlighted the vital role that formal and informal advocacy plays in addressing violence, abuse and neglect of people with disability. Recognising these factors, the Council of Australian Governments (COAG) in its **National Disability Strategy 2010-20** supported independent advocacy to protect the rights of people with disability (Area for Future Action 2.11). This commitment was reflected in the **Tasmanian Government's Disability Framework for Action 2013-17** (Area for Action 2.3.3) and in the **Disability Justice Plan for Tasmania 2017-2020**.

The Tasmanian community strongly supports the role of advocacy services in preventing abuse and neglect of people with disability. As noted in **Accessible Island: Tasmania's Disability Framework for Action 2018-2021**, people consulted wanted to see independent advocacy services retained and supported to assist people to access complaints mechanisms. "We need to remember that good support grows strong self-advocates", a participant in the community consultations noted.

What would the recommended funding deliver?

A. The funding requested would allow ACD to continue to provide independent advocacy services to families with children and young people with any type of disability or disabling condition when the current funding agreement terminates on 30 June 2020.

What ACD does

ACD is a state-wide and state-funded not-for-profit organisation. From our offices in Hobart, Devonport and Newstead, each year ACD works alongside hundreds of families across Tasmania who have children and young people aged 0-25 years with any type of disability or disabling condition.

ACD provides community leadership and quality family support options in Tasmania with a focus on empowerment, issue prevention and influencing continual improvement in societal outcomes for people with disability and their families and carers.

ACD was established in 1998. It provides:

- Professional independent advocacy services, as described in the next section, a representative form of advocacy in support of a child or young person with disability individual (ACD receives state funding from Communities Tas.);
- Community and Peer Education about rights and advocacy – Community development projects, community consultations, workshops and training that contributes to improvements in service and government policy and practice (ACD receives state funding from Communities Tas.);
- Case coordination (Fee for service - as an NDIS registered provider of Support Coordination services);
- Peer support, with a focus on shared life experiences and supporting families and young people with disability to gain skills and knowledge and confidence to self-advocate, to protect their (or their family members) rights, and to participate, contribute, lead, shape and influence their networks and communities. (ACD receives funding from the federal Department of Social Services - MyTime, and the National Disability Insurance Agency – Information Linkages and Capacity Building – DPFO peer support services);
- Information services (currently unfunded, with some assistance from Aurora Energy for our PEPTalk (Parents Empowering Parents Talk) magazine); and
- Training and consultancy services (fee for service).

ACD's overarching purpose is to work for continual progress towards a more inclusive society through the reduction and elimination of barriers to inclusion experienced by those with disability and their families and carers.

ACD's independent advocacy services

ACD is the only independent advocacy service in Tasmania that specialises in advocacy on behalf of families with children and young people with any type of disability or disabling condition.

Independent advocacy is the process of ensuring that the voice of people with disability is heard in matters that affect their lives. ACD works in accordance with the fundamental principle that the rights and interests of the child or young person with disability are upheld at all times. We recognise that families often experience issues affecting their child/children with disability or disabling conditions.

Empowering people: ACD support is designed to empower people to engage in decision-making to the full extent of their capacity, as opposed to substitute decision-making, which deprives people of control.

Family-centred: ACD is proud of its family-centred practice which recognises the family as a whole and respects the family as the owners of expert knowledge and skill in relation to their child or young person with disability and their family situation. We work to a Family Empowerment Model, a social model that focuses on strategies by which families use assistance to identify and achieve self-defined goals.

Outcomes-focused: ACD's approach is outcomes-focused. Our staff provide professional advocacy to support and/or act on behalf of families to resolve issues as quickly as possible. Where possible we empower parents and carers to build the skills and knowledge so they can make informed decisions, exercise their rights, and advocate successfully for their children with disability.

Handling complex cases: Often, cases handled by ACD's staff are complex, urgent, require substantial gathering of evidence, and involve engaging with several state and federal agencies. Two examples of the complexity of the cases handled by ACD's Disability Advocates, and the time and dedication involved in achieving satisfactory outcomes, are provided at **Annex 1** and **Annex 2**.

The volume of ACD's advocacy workload

In 2018-2019, ACD staff responded to 194 referrals from youth with disability (18 years and under), and parents, carers and guardians requiring advocacy and support to resolve 489 primary issues. While these numbers were slightly down on the 2017-18 figures (213 referrals to resolve 538 primary issues), they have continued to be high since 2016 and the cessation of the NDIS trial in Tasmania. Time spent resolving individual cases increased on average this year by 30 minutes due to the complexity of the issues people reported. In 2018-19, 44 per cent of children and families presented with issues that were assessed as having high impact and urgency (compared to 34 per cent in 2017-18, 32 per cent in 2016-17 and 20 per cent in 2015-16).

The direct time of ACD staff working alongside individual advocacy clients over the 52-week period, *not including* travel, research, community development activity, planning, file noting, and data recording time, was 3,105 hours for the year; an average of 16 hours per case. ACD advocates were able to assist 80 per cent of parents and carers within six months of referral.

Annex 3 provides data on the range of advocacy and information services provided by ACD in 2018-19.

Advocacy workload in relation to the NDIS

The NDIS is the most significant social reform in the disability sector in Australia in recent times. The NDIS has significantly improved the financial capacity of people with life-long disability and their families to purchase needed services, supports and equipment and technology. However, the NDIS is a huge social reform that will take several years to realise its full potential for people with disability. Advocacy services are critical supports for people with disability and their families to ensure positive systems developments and NDIS accountability.

ACD has been involved with the NDIS since it was called Disability Care and was the first funded Advocacy organisation in Australia to register with the NDIS to supply Support Coordination. Regular interaction with the scheme and parents and carers and young participants with complex disability across the community has resulted in ACD gaining vital expertise in this system and understanding its limitations and possibilities.

ACD continues to experience strong demand for its services in connection with the implementation of the NDIS as people with disability and their parents and carers grapple with and learn to respond to system failings and adapt to its processes and many requirements. This advocacy need is consistent with trends in other states and territories in line with evidence submitted to inquiries at the federal level and in other jurisdictions.

In its October 2017 NDIS Costs Report, the Productivity Commission emphasised that the NDIS relies heavily on well-informed participants who make decisions in their best interests. It said that if participants are unable to interact well with the NDIS, the benefits of the scheme will not be fully realised and this would have consequences for participants and their families, the financial sustainability of the scheme, and for the broader community.

The Productivity Commission also found that some participants (and their families) were finding it difficult to understand and interact with the NDIS. This accords with what we have been told by Tasmanian families. The Productivity Commission therefore concluded that disability advocacy was critical to helping participants engage with the NDIS.

Relationship to federal government funding

It is important to note that **no funding for advocacy services has been made available through the NDIS**.

In its October 2017 NDIS Costs Report, the Productivity Commission recommended that disability advocacy funding remain separate from the NDIS, and that funding of disability advocacy organisations by state and territory governments should continue, just like funding for other mainstream services. In the report, the Productivity Commission noted that any reduction in advocacy could impose real costs on the wellbeing of people with disability, their families and the broader community. In particular, the report noted the need for – and benefits of – advocacy services for people with disability who are outside the NDIS scheme, as well as those seeking to enter the NDIS as new participants and those who have exited the scheme.

The then federal Minister for Social Services, the Hon Dan Tehan MP, said in April 2018 that: “All people with disability still need to have access to state and territory individual advocacy services.” In the same media release, the then Assistant Minister for Social Services and Disability Services, the Hon Jane Prentice MP, said: “We must ensure all 4.3 million Australians with disability, regardless of where they live or whether they are an NDIS participant, have equitable access to independent disability advocacy services, to ensure their rights are promoted and protected.”

In line with these arrangements, the Tasmanian Government’s Budget Paper Number 2 for 2019-20 acknowledged that “disability support services that are outside the scope of the NDIS” including advocacy services “will remain the responsibility of the Tasmanian Government.” Advocates provide support to people with a disability, wherever they might be experiencing a problem or a difficulty. Many Tasmanian children and young people we work alongside are yet to be diagnosed or have disabling conditions that may not meet the NDIS criteria (44% in 2018-19) for access (e.g. people who experience the impacts of trauma, anxiety, depression, ADHD, conduct disorder, Asperger’s, brain injury, mild intellectual disability etc). These vulnerable Tasmanians with disability frequently fall through service cracks and present complex challenges to the community when accessing mainstream and universal services and systems. They often require advocacy for across-system issue resolution and successfully navigation.

While the NDIS has quickly become a greater focus for ACD and other independent advocacy organisations, the majority of issues that ACD advocates deal with relate to matters outside the scope of the NDIS. Of the 4 million Australians with some form of disability, it is estimated that only around 460,000 of them will be eligible for the NDIS. In other words, for every nine people with a disability, only one will be covered by the NDIS.

The federal Government, through the National Disability Advocacy Program (NDAP), has awarded grants to some organisations that provide independent advocacy services. **ACD does not receive any funding under the NDAP nor has ever had an opportunity to seek funding under NDAP**. In its report, the Productivity Commission recommended that state and territory funding of disability advocacy should "at least" match the per capita disability advocacy funding contributed by the Australian Government.

The wider benefits of funding independent advocacy services

In its October 2017 NDIS Costs report, the Productivity Commission recognised that disability advocacy provides a net benefit to the community but noted that data was lacking to support a more detailed cost-benefit analysis.

In September 2017, Disability Advocacy Network Australia (DANA) commissioned an independent cost-benefit analysis to assess the range of economic costs and benefits associated with the work of independent advocates.
The analysis found investing in independent advocacy leads to a range of benefits.

- Independent advocacy improves the lives of many thousands of people with disability, and this in turn benefits the wider Australian community.
- It improves the educational and employment outcomes of people with disability, allowing them to find more productive and better-paid work, with flow-on benefits to the Australian economy.
- It improves the capacity of people with disability to manage their lives while reducing the use of government services such as police and hospitals.
- It frees up resources in the justice system, the health system and the child protection system, and relieves pressure on accommodation services.
- It helps to relieve the load on carers and other service providers.

The cost-benefit analysis found that independent advocacy delivers substantial economic benefits exceeding its costs. It calculated the Net Present Value of independent advocacy as $589,498,000 in 2017 dollars. **This means that an estimated benefit of $3.50 is returned for each dollar of cost.**

Comparatively this is a very high ratio of benefits to costs and shows that independent advocacy represents a highly effective use of resources.

Why this funding is needed now

The current funding agreement with the Tasmanian Department of Health and Human Services provided for only 12 months of funding and it is coming to an end on 30 June 2020.

While the funding in last year's Budget was welcome, ACD needs funding certainty over the longer term for our day-to-day operations and in order to plan to meet advocacy demands, invest in the training of our staff, and to continue to engage with the community and with other stakeholders. Uncertainty over the continuity of our advocacy program is a cause for anxiety for our clients and members and we are at risk of losing highly experienced staff as they seek greater job security elsewhere.

It is vital, therefore, that funding for the coming years be provided for in the 2020-21 Budget to allow ACD to deliver these vital advocacy services to families across Tasmania and their children and young people with any type of disability or disabling condition.

Links between these priorities and the Government's long-term Plan for Tasmania's future

ACD supports the Tasmanian Government's commitment to a Tasmanian community that is inclusive, compassionate and responsive to the needs of its people. It helps to deliver on a number of specific commitments and priorities identified by a range of Tasmanian Government departments and agencies.

Continued State Government funding of ACD's independent advocacy services is consistent with the priorities outlined in **Accessible Island: Tasmania's Disability Framework for Action 2018–21**, specifically action 2.7: Support independent advocacy to protect the rights of people with disability.

ACD's independent advocacy services contribute directly to the achievement of the **Vision Statement of the Department of Health and Human Services**. Specifically, these services help people with disability:

- pursue their individual economic, civic, cultural, political and recreational goals free from discrimination;
- have their needs met by a person-centred disability support system;
- have their independence recognised so that they are able to make choices about decisions which impact on their lives; and
- participate meaningfully in policy development and legislation that affect them.

Funding of ACD's advocacy services as recommended in this submission would deliver on DHHS' commitment in the Vision Statement to:

- support individuals, families and carers to have greater control over matters that directly affect their lives and circumstances;

- promote health and wellbeing and early intervention where required;
- develop responsive, accessible and sustainable services; and
- create collaborative partnerships to support the development of healthier communities.

Funding ACD’s advocacy services also delivers on Outcome 2(b) of the **Disability Services Strategic Plan 2019–21 of the Department of Communities Tasmania** which states as an objective: “Enhanced choice, control and representation through funded advocacy services”.
Finally, as noted above, continued funding for the advocacy services provided by ACD would be consistent with the **National Disability Strategy 2010-20** and the **Disability Justice Plan for Tasmania 2017-2020** which both supported independent advocacy to protect the rights of people with disability.

The Disability Royal Commission

Prime Minister Scott Morrison MP announced in April 2019 the establishment of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

While the Australian Government announced that it would provide individual advocacy support for people engaging with the Royal Commission, this funded has been allocated to the Department of Social Services NDAP services only. This precludes ACD TAS, who will be required to engage families and young people with disability with the Royal Commission. As the only independent state-wide advocacy service in Tasmania that specialises in advocacy on behalf of families and children and young people with any type of disability or disabling condition, ACD has a lot to contribute to the Royal Commission, drawing on our wealth of experience and connections with family stakeholders in the community.
However, collating data from our nineteen years of providing advocacy services and engaging with potentially hundreds of past and present clients, places a heavy burden on our resources. In just one week, ACD devoted 27 hours of staff resource time, which included meeting with Advocates state-wide and the staff of the Royal Commission about the Hobart forums, preparing families to attend the community forums, preparing Board members and staff to meet with the Commission, and attending an after-forum debrief with Commission staff aimed at improving future forums.

Our continuing commitment will be vital if the experiences of Tasmanian families are to be reflected in the work of the Royal Commission and in its outcomes and recommendations.

The Tasmanian Government’s 2019-20 Budget identified the costs of providing information and evidence to the Royal Commission, and the costs of responding to its findings and recommendations, as a risk to the Budget. These demands also represent a risk to ACD’s resources. While it is impossible to predict at this stage the precise resource demands arising from ACD’s engagement with the Royal Commission, we ask that the Tasmanian Government make provision in the Budget for additional advocacy funding as required in the 2020-21, 2021-22 and 2022-23 years.

Annex 1: Case Study – Southern Tasmania

Age and Diagnosis:

A boy, 12 years of age, with no conclusive diagnosis but symptoms of ASD, ADHD and Global Developmental delay. IQ of about 45. Child is very overweight, and this may be a feature of a yet undiagnosed condition. Child has significant behaviours of concern and challenging behaviours. Child will hit, punch kick, bite and push others. He also absconds and has been known to try to get into neighbour's houses by kicking in doors/windows. He is incontinent and vomits/regurgitates food frequently and may spit vomit or throw vomit at others.

Residence and family:

The family live in a Hobart suburb. The boy resides with his grandmother, older sister (who has a diagnosis of autism) and older brother. His mother lives separately but visits regularly. His grandmother has a serious heart condition. Due to the child's behaviour they must keep the house doors locked and maintain high vigilance at home. In the home context, he needs to be supported 2:1 as well and his grandmother is assisted at times by one or both of her sons who visit weekly. One of her sons has an intellectual disability.

Exclusion issues:

The family has accessed ACD Advocacy Services since the child was seven years of age, and NDIS Support Coordination at 10 years of age.

Following ongoing exclusion from a private school setting, the child was enrolled in mainstream primary school but, as a result of his behaviours at two different primary schools, he was deemed to be a significant risk to himself, other students, teachers and the school building and furnishings. He was also deemed to be a risk to the schools' neighbourhoods. The risk assessment stated that the student could not attend school unless he was supported 2:1.

As a result, he was subject to frequent suspensions and then reduced hours at school culminating in prohibition. After prohibition, the alternative learning plan for this student was to attend the support school (some distance from the family home) for ½ hour, 2 days per week with a plan to increase his time at school slowly.

Exclusion impact:

The reduced school hours placed a significant burden on his grandmother to supply care for him all day every day. There was also a problem regarding getting the child to school for the short time as the grandmother does not drive and the child needs to have a person in the passenger seat with him as he interferes with the driver and the car controls and/or tries to leave the car while it is moving. Although he did use the special school bus, ultimately his behaviour resulted in this service being withdrawn. Transport, in-home support and respite became the most urgent needs for the family.

The stress of the child's needs has undoubtedly contributed to the grandmother's ill health. Should the grandmother's health deteriorate further, there is a risk that the child will need to be cared for by the state.

Systems and types of services involved:

Anti-Discrimination Commission involvement in 2015 and subsequent agreement through conciliation to work to remediate exclusion issues. School agreeing to refund school fees paid and put in place professional development for teachers and principal.

During the time of the breakdown in the primary school placements, the Disability Advisory and Assessment Team became involved for support and assessment. This assisted with getting NDIS funding for support and further assessment and therapy.

The NDIS funding made it possible for 2:1 support to be put in place for a few hours per day and to transport him to school. Due to the short time at school initially, support staff had to stay on school premises to transport him home. Over time, he was able to increase time to three half days at the special school. The DoE were able to set up a unit for him at a high school where he had two teachers and a secure space. After a while, the special school decided that the high school was a better placement for him and discontinued his attendance at the special school. They cited the boy's verbal skills and need for contact with peers even though this is not a feature of his presence at the high school – he is completely separated from other students at this time.

A reduction in NDIS funds and a partial breakdown of the support service provision led to the decision to use 1:1 support and taxis to transport him to school and to therapy. This is working well although the taxi service has charged for cleaning the taxi at times due to vomiting.

It has been difficult to set up respite. The service provider who provided support staff made their respite unit available, initially at weekends and then on a weekday afternoon. Weekends were unmanageable as the child became distressed and could not share the unit with other clients.

The weekday afternoon arrangement went on for a while but ultimately broke down because of the damage the boy did at the unit and because of problems with staff. Support during school holidays must be in home which is limited by lack of space.

Therapy was obtained through an ABA therapy provider who worked with the family in home and in the respite and school contexts. The therapist was unable to work in home because shortly after they started to work with the child, the grandmother became very ill and was hospitalised. Since then therapy has been held daily in the therapist's rooms and once per week at respite until that broke down as well. Therapy is resulting in some improvements in the child's learning and behaviour, but this is still very context driven.

During the time of the grandmother's hospitalisation, DoE submitted a notification to Child Safety Services due to the risk he would lose a carer. CSS deemed – following assessment and consultation – that with the funding from the NDIS, the child would receive supports that would enable the family to manage. The family is also very reluctant to engage with Child Safety Services.

System and service gaps and barriers to inclusion:

In all contexts, two or more people are needed to support and care for the child adequately. He desires the company of other children, but it is difficult to keep everybody safe to allow for this.

Although the child now attends school every morning from 9-11am and therapy from 11- 1pm, in-home support and respite are still vital. Although the NDIS has provided a reasonable plan, the funding for coordination of supports has not been enough to provide the high level of coordination required for this child particularly in times of crisis. As soon as it was evident that this was the case after a crisis which led to the child being suspended from school, a review of the NDIS plan was requested. This took some months to be responded to and a review is underway through the Complex Pathways process with NDIS It has been over one month, and we still do not have a new plan and thus no funds to provide support coordination. As of the time of writing, the child is suspended from school for kicking in a door. He can return once a new door is put in. This latest suspension has resulted in more coordination being required, which is not funded.

The service provider contracted to provide support workers also provided, through their behaviour management team, assessment and a behaviour management plan, and training for the staff. This service ended with the next NDIS plan, and the ABA therapy service took up behaviour assessment and planning and continued to train the staff. However, staff changes, and inefficient service from the provider, led the grandmother to ask for a change in service provider. Coordination of Supports has sought a different provider, but once the child's behaviours have been disclosed, all other providers have said that they do not have capacity to support the child.

Gaps therefore are:

- Insufficient funding for coordination of supports.
- Insufficient education spanning a 5-year period – no suitable full-time program and environment.
- No specialist multi-disciplinary team for behaviour assessment and ongoing management and training (State Government Disability Advisory and Assessment Team disbanded).
- Insufficient services available – withdrawal of services and service refusal to work with the child because of behaviours.
- Insufficient skilled human resources.
- Insufficient support services that can focus on the family.

Annex 2: Case Study – Northern Tasmania

Please Note - This case example has been prepared by ACD TAS Advocate, Gary McMurtrie, with the knowledge and consent of the client's mother. While the names have been redacted, the case will be identifiable from the information presented. We therefore ask that this submission be treated as CONFIDENTIAL.

Age and diagnosis:

The client is a 12-year-old boy with ADHD, ODD, and a moderate intellectual disability (FSIQ of 48). The client also has a complex trauma-related history. The client currently lives at home with his mother in northern Tasmania. The family home is via Housing Tasmania. The client's father lives in a men's shelter in Hobart, along with the client's teenage sister.

The client has been experiencing and displaying significantly complex, challenging and escalating behaviours. The client's behaviours include threatening self-harm, actual harm to animals resulting in involvement by RSPCA and police, plus verbal and physical harm directed towards others.

Before the involvement of an ACD Advocate, the client and his mother had been cut off and isolated from education since May 2018, as well as from all NGO support services, and the community. Professional agencies such as Child and Mental Health Services would not allow the client to attend their premises in 2018, because of the risk of harm to staff and clients. A well-known therapy provider withdrew support staff because of the risks. Respite also broke down because the client obtained items that could be used as weapons and threatened staff plus self-harm. The client was admitted twice to the adult ward of the Northside Mental Health Clinic in Launceston, where the client was administered adult levels of medication.

Systems and types of services involved:

The ACD Advocate has involved and brought together the Tasmanian Department of Education, NDIS, Disability Services, Child Safety, RSPCA, Tasmanian Police, Tasmania Health, CAMHS, Launceston General Hospital administrative and medical staff, a key psychologist, and the client's NDIS-contracted forensic psychologist.

A cross-sector meeting was initially held in 2018. There was agreement that the client and his family were in crisis, with the client being at significant risk to himself and others. The client was set to enter the juvenile justice system, resulting from the involvement of police and charges by the RSPCA. With the support of the ACD Advocate, agreement was reached to hold those charges in abeyance and a new automatic and agreed upon brief was provided for any attending police, so they would know how to respond to the client. However, further police involvement has not been necessary because of the ACD Advocate's work in getting Government and NGOs to work collaboratively together to create new support options and programs.

The client's home was reviewed by an occupational therapist and has been made secure. The initial premise had a new fence and locking storage for dangerous items installed, plus a duress alarm. Unfortunately, there was a shooting incident at the property by unknown persons, resulting in a further move to a smaller Housing Tasmania property, which was not adequate in terms of rooms for the client and his mother, and to allow for in-home overnight respite, which was ceased. The client’s sister moved to the home in 2019, exacerbating the space issue and service provision.

A specialist support program was developed and introduced to allow the client to reengage with activities and community opportunities via state funding to a disability provider.

The client was excluded from primary school in March 2019. The DoE approached the PCYC in 2019 about their outreach program but were advised by police that their officers would need to be armed, which was not deemed as suitable for the client or other children. DoE enrolled the client in Eschool in Term 2, 2019, as no other option was deemed suitable. The family and disability support staff have both advised that they do not consider themselves qualified to deliver or support the client’s education via ESchool. The ACD Advocate requested a copy of the learning plan. This will require further advocacy as to date this has not been received.

NDIS: The client’s first NDIS plan was issued in 2018. Provision was made for Support Coordination, who referred the family to the ACD Advocate following her very first meeting with the client and his mother. The NDIS provisions for Support Coordination were quickly exhausted by the complexity of the supports required. Difficulty in accessing suitable services continued, particularly as the client and his mother were in a constant state of crisis, with the client threatening harm to himself and others.

The NDIS plan was twice revised, the second time administratively without any consultation with the family or the client’s Advocate. The resultant NDIS plan was insufficient to meet the client’s needs. The ACD Advocate assisted the family to request an internal review of the administrative plan decision because:

- The family was not consulted;
- The State Government was the only entity reportedly consulted;
- The objectives used were from an earlier plan and did not reflect current circumstances; and
- The resource allocations were considered inadequate by the comprehensive cross-sector professional support groups and did not reflect recent and likely future support costs.

As there was no NDIS action or acknowledgement for two months, the Advocate again submitted the request.

As a result, and after significant delay, a further NDIS plan review was conducted, which included participation by the client’s mother, the ACD Advocate, the Child Safety and therapy providers and the client’s Support Coordinator.

NDIS representatives were invited to attend all senior level cross-sector meetings concerning the client and presented at half of the meetings. It was clear that a much wider and more detailed NDIS-funded behaviour plan was required to ensure the safety of the client, his mother, support staff, and community members and to allow the DoE to create a re-entry program for the client’s education.

As a result of ACD advocacy, the quote for the required behaviour management plan was finally able to be put forward in the long-delayed NDIS Internal Review meeting. However, the behaviour management plan was not completed for 12 months, creating further risk to the client, the community and support entities.

Exclusion issues:

Since early 2018, the client has been excluded from full-time education, traditional community support services, including specialist agencies such as Child and Mental Health Services, and from most day-to-day activities in the community. Disability providers supply two part-days of staff support a week, but safety concerns and lack of suitable home premises precludes overnight respite.

System and service gaps and barriers to inclusion:

There is currently no specialist facility in Tasmania to cater to children like the client, who exhibit high-end behaviours of concern. Similarly, there is a real lack of suitably trained staff in the professional, education and service sectors to work with a child like the client. Initially, there was a gap in any sort of global case management and communication, which the State Government funded on a trial basis. DoE says they have no suitable facility for a child like the client, and no specialist staff to visit the home to support ESchool enrolment.

Exclusion impact:

This client is one of many children with very complex needs and behaviours of concern in Tasmania accessing ACD Advocacy. Service gaps and exclusion from mainstream and specialist services, programs and pathways to appropriate supports, further isolate these children and their families and place them at significant risk and disadvantage.

The client's mother carries most of the burden for this child's care and the management of his very challenging behaviour. The client and his family remain isolated and even targeted by their community, with multiple incidents in 2019 where local residents have been so agitated that the police have needed to be called to intervene.

Annex 3: ACD Independent Advocacy Services 2018-19

Snapshot of ACD advocacy services, 2018-19.

194	Referrals from parents, carers, guardians
489	Primary issues resolved through Advocacy and Support
3,105	Total hours of direct ACD staff time alongside individual and family Advocacy clients over the 52-week period (not including travel, research, community development activity, planning, file noting, and & data recording time)
16	Average hours per case (increase of 30 minutes per case compared to the previous year due to the complexity of the cases
88	Percentage of children and families presenting with issues that rated as having high (44 per cent) or medium (44 per cent) impact and urgency.
497	Information to inform and empower – requiring less than 1 hr. of staff time

Families accessing ACD Advocacy continued to present with serious at-risk indicators across a number of life domains and reported experiencing inclusion and participation and access to services and systems issues for their children and young family members with complex and high support needs. This year, ACD Advocacy experienced an increase of more than 125 per cent in referrals from families accessing with children under the age of 6, many of whom reported not being able to gain assessments and needed therapies.

Table 1 shows that of the children requiring Advocacy, 38 per cent experienced daily impacts from multiple disability and/or disabling conditions reported as, post-traumatic stress, anxiety, learning disorders, oppositional defiance disorder, depression, ADHD, conduct disorder, Asperger’s, chromosomal disorders, autism spectrum, brain injury, and intellectual disability.

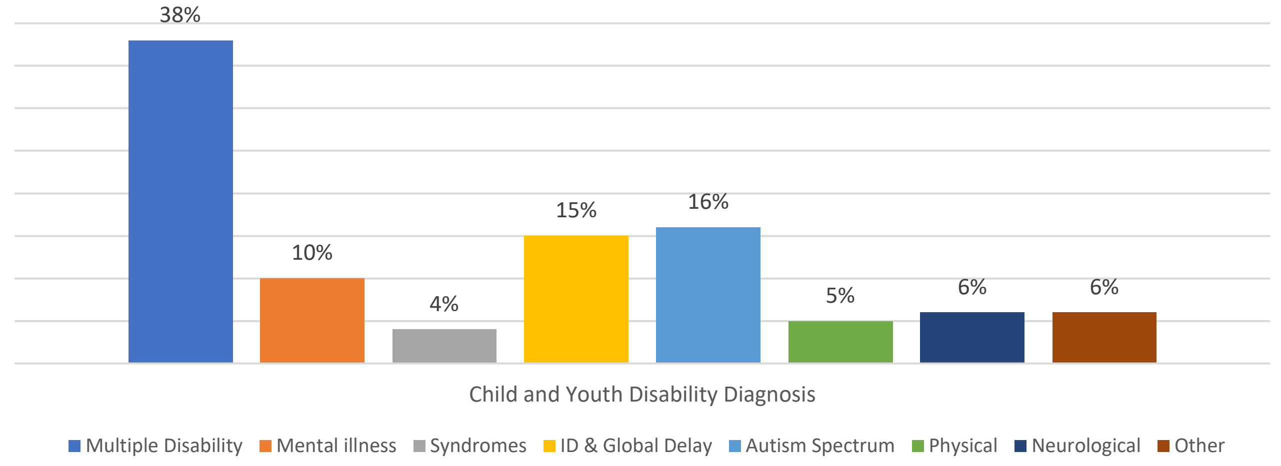


TABLE 1: 2018/2019 DISABILITY DIAGNOSIS REGISTER OF CHILDREN AND YOUTH ACCESSING ADVOCACY

Of these children (and their families on their behalf) 44 per cent had not applied for – or had not met the NDIS criteria for – access. Many of those who have applied reported a delay in access due to waiting lists for assessment and diagnosis to gain evidence of permanent functional impairment. The wait for vital intervention and therapies is an obvious concern. Access to Health and Mental Health primary issues (13 per cent) were dominated by lack of allied health, paediatric, psychology and psychiatry, and adolescent mental health services, including outreach services.

Of the families accessing Advocacy, 56 per cent disclosed that they were registered with either Early Childhood Early Intervention or had an NDIS plan and 45 per cent lived more than 40 minutes' drive from services and supports.

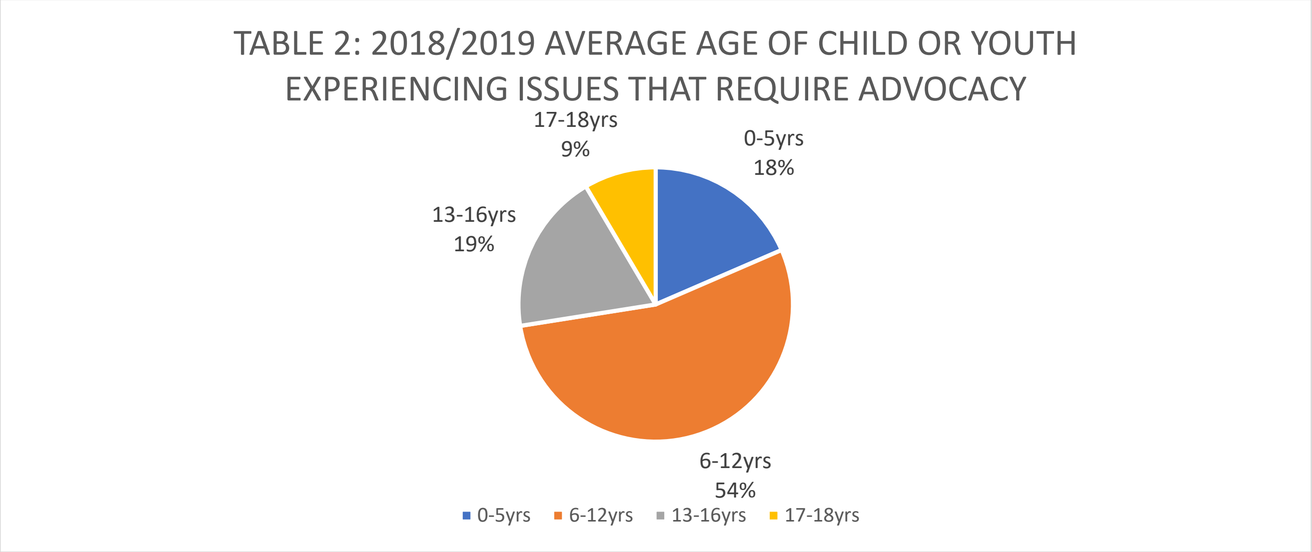
ISSUE IMPACT AND URGENCY AT POINT OF ACCESS

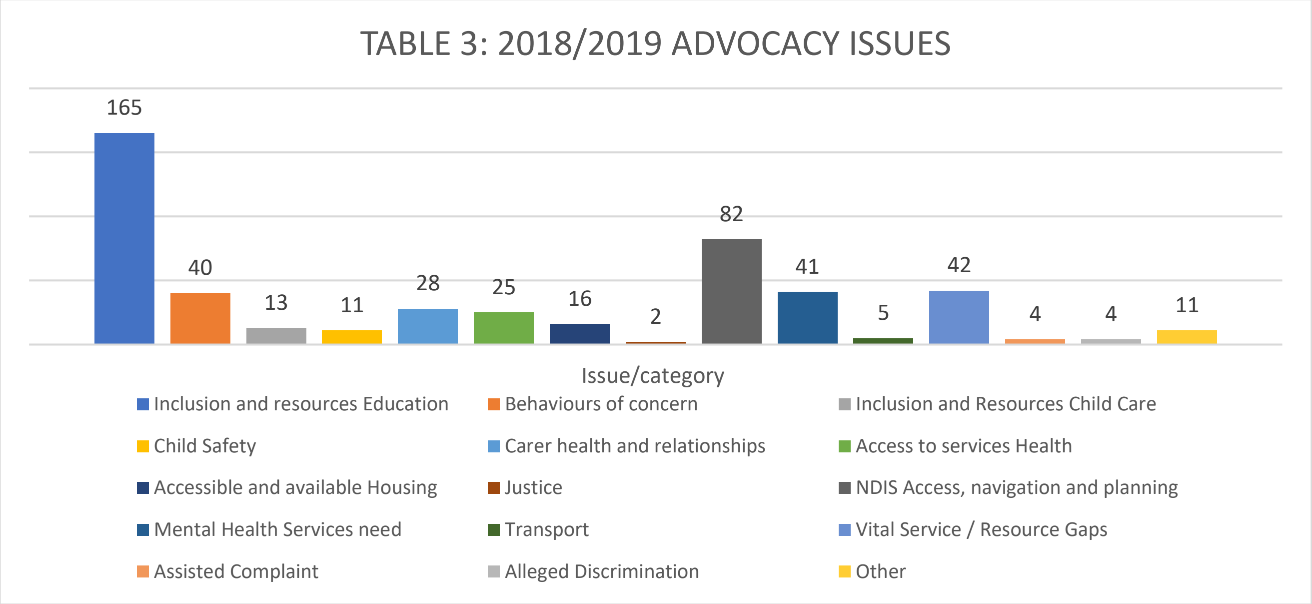
In 2018/2019, 44 per cent of families and carers who self-referred to ACD Independent Advocacy were assessed by staff (using ACD's impact and urgency matrix) as presenting with primary issues with high urgency (need for immediate response) and high impact (serious issues of risk evident) ratings. This compares to 34 per cent in 2017/2018, 32 per cent in 2016/2017 and 20 per cent in 2015/2016 and continued to demonstrate the significant distress and impact on carers raising children with complex disability and high support requirements. Situation assessments for many of these families shows an overall picture of poor inclusion for their children with disability across many needed services, and particularly education and health.

It is positive that following Advocacy intervention in 2018/2019 85 per cent of clients at exit were assessed as being in the Low urgency/Low-Medium Impact range, but we remain cautious as this is a 10 per cent drop from the previous year and again, we believe, reflective of increasing issue complexity and service and system gaps.

All Advocacy clients were surveyed at exit by phone, email survey or in person this year. The average satisfaction survey rating was 8.5/10 and for people surveyed verbally or by email correspondence, 9/10 reported satisfaction with the advocacy outcomes gained, being prepared to proceed on their own, being more informed and confident to deal with issues, and being prepared to return to ACD if needed.

Tables 2 and 3 show that most parents and carers continue to access ACD advocacy services after their children reach school age and require assistance to work through and resolve issues experienced across a number of specialist, mainstream and universal services, systems and environments.





ACD Advocacy continued to be under resourced to meet demand in 2018/2019 with 39 people asked to wait for up to 2 weeks to receive this assistance. On many occasions ACD utilised our Peer Support staff, Case Coordinators, Communications Officer or Program Manager to assist and support waiting families by telephone to avert crisis and prevent further stress. In order to respond to the high percentage of those contacting who required an immediate response or had serious issues of risk evident, staff continued to report occasional after- hours or weekend contact, phone or video conference attendance at case meetings and one-off urgent planning to prepare people to attend meetings by themselves (when Advocates were unavailable). Advocate face to face team meetings were reduced whilst virtual meetings through video conferencing were increased to save time and money.

Staff worked to bring about assisted outcomes and successfully closed **184** cases this year alongside parents, carers and guardians and in collaboration with many.

Education issues continued to dominate presenting issues at 33 per cent and NDIS issues at 17 per cent. ACD Advocacy had an increase of new families, with 40 per cent of clients reporting accessing the program for the first time. Data suggests families are being referred to ACD from many sources, including mainstream services, government, not for profit, private industry and community sectors and individuals. Family distress continues to be evidenced with reported issues in behaviours of concern (>42%), vital service/resource gaps (>35%), Health and Mental Health (>73%), Carer Health (>100%), education inclusion and resourcing (<6.5%), NDIS (<18.8%).

The ACD Peer Support area had a reduction impact on some of the Advocacy data in Southern Tasmania; with 20 per cent of information calls in the third quarter of the year fielded by Peer Support and Senior staff when the caller was capable and confident to act for themselves after receiving information and/or resources. Eighty per cent of these contacts were for queries about education, health, NDIS and housing engagement or service matters.

Advocating for an NDIS system and processes to effectively respond to people in crisis was a priority for ACD this year as 5 per cent of children requiring Advocacy and Support Coordination presented in crisis with multiple disability diagnoses and undiagnosed mental health conditions. The ACD worked with State Government Disability Services, Health, NDIS, Child Safety and community disability organisations to respond urgently a number of times. ACD's role in many cases is to undertake risk profiles, gather evidence and bring these families to the attention of relevant senior State Government and NDIS officials as quickly as possible to ensure they are kept safe, and receiving services and supports. This year saw health system and emergency accommodation gaps continuing to present, and with the loss of regional office disability services and Disability Advisory and Assessment Teams, the loss of specialist and experienced staff, assessment, behaviour intervention and planning and training gaps became more evident.

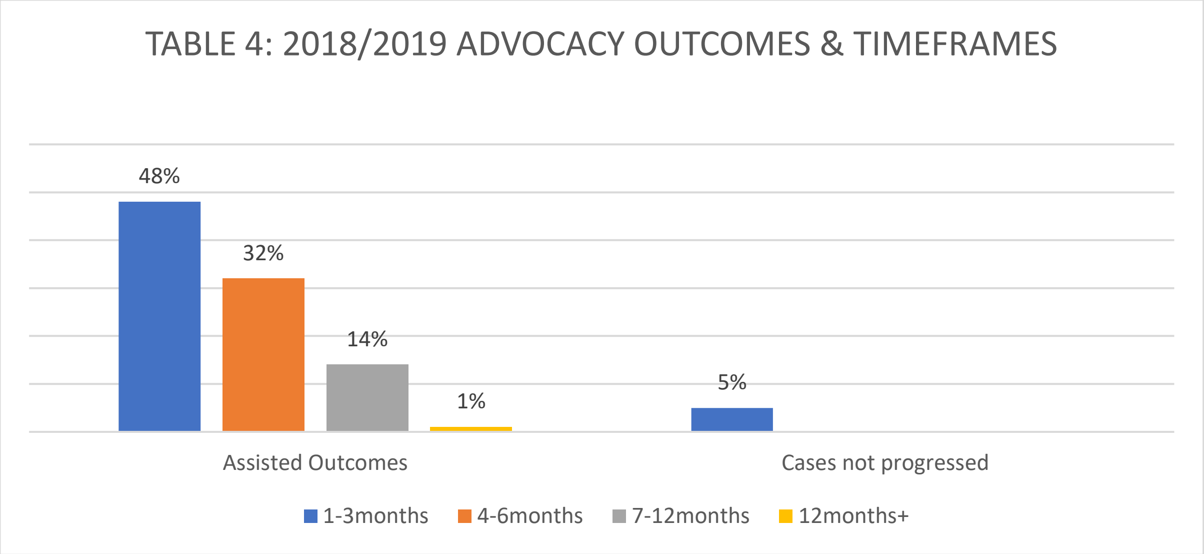


TABLE 4: 2018/2019 ADVOCACY OUTCOMES & TIMEFRAMES

ACD Advocates were able to assist 80 per cent of parents and carers within six months of referral. The number of cases not able to be progressed within this 12-month period increased by 6 per cent.

Data demonstrates that ACD Individual Advocacy is an effective intervention and prevention service; assisting 48 per cent of clients to positive and wanted outcomes for their child/ren across a number of specialist, mainstream and universal services, systems and environments, within three months of referral.

TABLE 5: 2018/2019 REPORTED BARRIERS TO ACHIEVING OUTCOMES WITHIN 6 MONTHS OF REFERRAL.

Education	-The Education facility cannot make the necessary adjustments or supply the financial resources to facilitate full-time education attendance. -DoE Risk Assessment - Children with disability and challenging behaviour deemed a risk and excluded from education. -Lack of system human and financial resources to provide timely assessment and/or intensive short-term therapy or intervention to meet the needs of students with disabling conditions and inconclusive diagnoses who are not eligible for the SDR. -Positive Behaviour Strategies not implemented - repeated use of external suspension led to parents moving their children to other schools.

	-Policy – Mainstream school can refuse intake of child with disability as it is out of their zone. -Waiting list – Support School -Ineligible – Support School
Housing System/Stock Resource	-Public housing stock is not available to meet the needs of families with children with disability who have specific requirements. -Housing modifications are incomplete. -Private rental – Will not approve funded house modifications to be completed and does not renew the tenants lease.
Health System/No appropriate Facility/Human resources	-Secure hospital ward for adolescents is not available to admit children and young people at risk of harming themselves and/or others. Children taken by Police to Hospital Emergency or admitted to an adult ward. -Wait list - Cannot access Child Psychology Assessment and Behaviour Management Plans. -Wait list - Cannot access TADS assessment -Wait list - Cannot access a Paediatric Specialist, must travel interstate. -Wait list - Cannot access an Occupational Therapist for recommended treatment.
In home and Community Support/ NDIS and continuity of support policy	-Cannot gain assistance to receive a diagnosis for access to the NDIS. -Cannot access funded NDIS Support Coordination to assist when a Participant carer requires urgent hospitalisation. -Insufficient Plans - Waiting time following a review of a reviewable decision exceed 6 months. -Policy - No person response - NDIS complaint is not actioned past initial receipt stage. -Funds exhausted in NDIS plans and person who is self-managing and in crisis waits for 4 months for plan review and may incur debt.
Childcare System/ Service Gap/skills	-Vacation care and Outside School Hours Care are not available or cannot accommodate the care and support of a child with significant support requirements.

Community Specialist Support Gap	-Finances – parents cannot afford to pay for the cost of transport from Respite to school and/or for community activities. -No services are available to supply urgent behaviour intervention outreach, residential or respite support. -No on call services are available to supply across system Lead Coordination/Case Management for those in crisis. -Kin ship carers with informal arrangements are unable to advocate on behalf of their family members with disability across the community (where a legal guardian is required) and cannot gain financial or other types of essential carer services.

COMMUNITY DEVELOPMENT AND SYSTEMIC WORK

Proactively, ACD staff represented the best interests of families in the Advocacy area by time spent, evolving innovative ideas and participating in and/or undertaking community development projects. ACD is involved in many peer networks, strategic alliances, working and reference groups and committees, and writes submissions to Government to influence and suggest ideas for addressing key issues affecting families and children and/or young people with disability across Tasmania.

Community development and awareness raising in order of most resource time spent:

(1) Continuity of care and support (guardianship maintenance) for families and children with high and complex needs – State Gov. NDIS. Child Safety. Health.

(2) The NDIS systems and processes development – NDIS Advocacy Network and consultations (Intermediaries Providers) and forums (Make it work), Quality and Safeguards.

(3) Child Safety - Strong Families Safe Kids and Child Safety and Advocacy Network.

(4) Disability Voices Tasmania – Developing a Tasmanian Disability Peak Body mechanism.

(5) Advocacy – National Conference and Networking with Children and Young People with Disability Australia, ACD VIC., Disability Advocacy Network of Australia, Speak Out Advocacy, Advocacy Tasmania and Citizen Advocacy.

(6) Disability awareness – Schools - Fairer World. TAFE. Across Community – PEPTalk publication.

(7) Positive behaviour Workshops for Families.

(8) Kin Raising Kids – Strategic Planning assistance.

(9) Family and Carers Peak Advisory Council – Representative voice (Disability).

(10) Transport - Taxi Transport scheme.

(11) Accessible Playgrounds – Variety Tas.

(12) Sport and Rec. – Communities Sport and Rec.

(13) Education Funding – Area Enrolment and Funding Model.

TABLE 6: SYSTEMIC GAPS REPORTED IN 2018/2019 WHERE COMMUNITY AND/OR GOVERNMENT DEVELOPMENT WORK IS NEEDED

Independent Advocacy in Tasmania

2018/2019 GAP - Beyond July 1, 2020 there is a verbal commitment only from State Government to continue to fund Independent Advocacy in Tasmania for people with disability and their parents and carers.

*Note – The ACD is uncertain of Advocacy funding arrangements from 1 July 2020, with demand set to increase during the next 3 years because of needed Advocacy to find and supply information from past cases as required, as well as to prepare for and support submissions to the the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. Precious human resource time throughout 2018/2019 was spent campaigning to secure funds for 2019/2020.

Child Safety

2018/2019 GAP - Independent Advocacy service availability to take referral from the Children's Advice and Referral Alliance (CARA) - in 2019, name change 'Strong Families Safe Kids'.

*Note – the State Government funded an Independent Child Advocate to sit under the jurisdiction of the Secretary for Child Safety. This role is available to provide Advocacy to those children within the care and protection of Child Safety and those who are at imminent risk of entering the system and is making a significant and positive difference to many children.

ACD, Child Safety Directors and Managers, within limited availability collaborate, to improve outcomes for individuals with disability in the child safety system and when intersecting with other systems across the community. ACD engaged with Communities Tas. (State agency) and the Strong Families Safe Kids project.

GAP: Service of last resort is not evident for children with disability under the age of 18 or those over the age of 18 who are leaving the care of Child Safety without natural supports.

*Note - The state is/was (?) considering extension of care to age 21 for some young people. This now seems in doubt. The NDIS provision of Specialist Disability Accommodation to people over the age of 18 is rare, making it difficult to effectively transition and support some young people in care who have high or complex support needs into fit for purpose accommodation. Transition planning and arrangements need to begin at 16.

Family Support

2018/2019 - GAP: Family centred practice, case or lead coordination/management to assist in the event of family crisis or complex situations. *Note – Community options case management is not available to people with disability. Families cannot use plan funded NDIS Support Coordinator to assist when Participant's parent or carer requires urgent assistance. The NDIS have developed a complex participant pathway, and the ACD have been participating in the early stages of roll out in Tasmanian alongside several children across the state. Monitor.

GAP: Outreach, Behaviour Assessment, Management and Training Services. *No services are available to supply urgent behaviour assessment, intervention outreach, residential or respite support in support of families and children with serious behaviours of concern. Families report resorting to calling the police and/or taking their children to hospital when in crisis. The State Government is reviewing service gap areas. The NDIS red tape seems to have presented significant barriers to both state and out of state practitioners registering. Insufficient specialist human resource availability and waiting lists are having a significant impact on families, which in turn, is having impacts on Health, Social Services, Child Safety, Education, Housing, Family and Relationships, Justice systems and Disability Services.

GAP: Centre Based Respite – Funds exhausted in NDIS plans. Mainstream programs refuse services to people in need of urgent respite because they have an NDIS plan, despite no funds being available for Respite in their plan. *Note the NDIS does not support families with needs for centre based respite access for children under the age of 12. The NDIS reports that mainstream services apply (Childcare, vacation care etc.) and that anything outside this is parental responsibility. This is having a specific impact on those with children with high and complex needs, including families with children who have behaviours of concern, and a flow on effect to the Child Safety and Health systems. Monitoring.

GAP: Financial and other types of essential services for 'informal kinship carers'. *Note - Informal' kin carers do not have legally binding court orders in support of their care arrangements. Although they have all the same responsibilities and needs as a 'formal kin carer', they do not have the same rights. Most kinship carers look after children and young people who have been abandoned or removed from their parents because of abuse and neglect. Many children in kinship care have disability or chronic illness. Many kinship carers become frustrated, particularly through the critical early development years of the children in their care, as they experience barriers to accessing needed assessments and services (such as Health and Education). Gaining guardianship status is often a long and expensive process, with many other complications that many kin carers are afraid to take on for fear of their kin being removed and further traumatised. Projects continue alongside Kin Raising Kids to raise the kin Care profile and determine possible support solutions.

Health

2018/2019 - GAP: Timely Assessment and Early Intervention therapies and services. *Note - Families report long waiting times to gain needed therapy and assessment or no service availability. This gap is increasingly more evident across the North West and North of Tasmania. This is affecting many awaiting diagnoses for access to the NDIS.

GAP: Comprehensive medical and psychological health, and medication review and management of children cannot be accessed when needed. Secure hospital wards for adolescents are not available to admit children and young people at risk of harming themselves and/or others.

* Note - Minister Ferguson 2017/2018 committed child and adolescent mental health funding and facilities. There is no new funding for this initiative in the 2019/2020 budget. This requires more investigation and consultation.

Child and Adolescent Mental Health Service (CAMHS) in the NW suggest that a sensory and de-escalation ward is needed as well as support from the Health system to extend the Child Health Nurse remit beyond the early years.

Education

2018/2019 - GAP: Models of education and environments that provide for students with disability who exhibit complex or potentially harmful behaviours. *Note – The new adjustments funding to begin 2020 may effect a positive change in government schools where adjustments have not been implemented successfully due to lack of resources. *Note - The state education system is looking beyond e-school to support options for children who present as an education challenge in standard educational environments. These new situations and settings seem at this stage to be reactive and without models of practice or best research alongside in support. There are many Principals, Teachers, Support Staff, Psychologists and Allied Health Professionals in the system with the determination, knowledge and expertise to meet this challenge if it is included as a specific strategic objective. There is also a possible policy barrier in the state education system preventing the recruitment of suitably skilled and proficient People Managers, Allied Health and other relevant Professionals to Principal positions. This could be reviewed, although as we understand it, is a strongly held Education Union position.

GAP: Human and financial resources to provide for timely Psychological assessment and intensive but short-term therapy or intervention to meet the needs of a student with disability. *Note – school resources are tied up with child assessment.

GAP: Disability awareness and experienced and skilled Teachers and Support Teachers.

*Note - The State Education Dept. is working in partnership with UTAS to support development of Post Graduate options.

The State Government has signed off on a bi-lateral National School Reform Agreement (NSRA) agreeing to a way forward for education funding reform in Australia. These reforms include funding schools according to student needs. The Agreement began on 1 January 2019 and will expire on 31 December 2023. Tasmania signed the agreement on 6 December 2018, and as a result will benefit from four hundred and ninety million dollars in funding over ten years. This will provide resources for students with the greatest needs and enable government schools to make necessary educational adjustments for all students with disability. The new education adjustment funding model begins in 2020 in Tasmania. Teacher training will be considered when required as part of the individual adjustments required for students.

GAP: Early Child Hood and Childcare, Vacation care and Outside School Hours Care are not available or cannot accommodate the care and support of a child with significant support requirements. *Note - The NDIS takes the stand that the Early Childhood Education and Care (ECEC) sector should be inclusive. This is at a standstill. The Aus. Gov. Inclusion Support Program will be reviewed in 2019/2020. The presenting issue remains because the sector is insufficiently resourced and skilled in many cases to make the needed accommodations for many children to be included. Research is required on the numbers of children with disability accessing these services.

NDIS - 2018/2019

GAP: Informal Nominee status: NDIS Legislation results in parent and carer nominee influx in requests, for what in some cases will lead to unnecessary guardianship of young people with disability (18yrs+). *Note - NDIS is trialing a capacity assessment tool.

GAP: Insufficient Disability Specialist Services and NDIS registered providers.

*Note - Service contraction and gaps are evident (in the NDIS provider market) with unmet needs of people with intervention, and high and complex needs. The market is not growing quickly enough to meet demand. Pre-NDIS issues remain; lack of disability specialist services and skilled workforce. *Note - NDIS and State Government review of available therapy services has been completed. Result unknown - but thin market consultations and development work have been instigated by the NDIS. Research into needed professions and services to meet expected Tasmanian Participants demand is underway to inform UTAS of a potential market.

GAP: Travel. Parents and carers cannot afford to pay for the cost of services to transport their children from out of home Respite to school and/or community activities.

*Note – previously block funded Disability Services providers purchased and maintained organisation vehicles for transporting their clients. The NDIS hourly rate to provide a service does not take transport needs into account, leading to many providers retracting transport services and many parents and carers and children not accessing needed services on weekdays. Unsupported taxi transport is not appropriate for many children with disability. This needs further ACD review as NDIS hourly support rates increased at 1 July 2019.

Housing – 2018/2019 - GAP: Public housing (accessible) stock is not available to meet the needs of families with children with disability who have specific requirements.

*Note - The effects of the lack of housing available for Tasmanians is being experienced by many on low incomes without home ownership. Additional impacts are being experienced by parents and carers who are unable to afford and/or source accessible accommodation or gain timely home modifications or approvals for home modifications to private rentals.

Across System - 2018/2019 - GAP: Education exclusion, and insufficient Disability Specialist Services and NDIS registered providers.

* Note - Parents and carers report being unable to work full time or part time as a direct result of child care needs due to; early education and childcare or education exclusion; no service capacity; or no available services and supports in area. Parents report financial distress as the cost of living rises.

TABLE 7: INFORMATION PROVISION SUMMARY 2018/2019

	Number Of Advocacy Information Requests	No of posts	FYW articles and resources
Service, system, support, resource, Information navigation	201		
Documents & Info that assist to plan and/or self-advocate	121		
In crisis Behaviour support and information	25		
Guided Referral	68		
Disability Specific Information	49		
In crisis family support to siblings or others	8		
Request for submission or consultation	25		
Facebook articles posted that inform and empower		680	
PEPTalk magazine information and support articles		380	
Finding Your Way posts, page articles and Getting Ready booklet information (Housing and Employment) – Information for community engagement purposes.		118	315
SUB TOTAL	497	1178	315
TOTAL			**1990**